

“Washington County Longevity Forum: The Aging Dilemma in a Rapidly Changing Environment”

Name of Event: End of Life Care Sub-committee

Date of Event: August 16, 2005

Location of Event: Western Maryland Hospital Center
1500 Pennsylvania Avenue
Hagerstown, MD 21742

Participating Organizations: Hospice of Washington County, Inc
Palliative Care Services @ Washington County Hospital
Somerford Assisted Living & Alzheimer’s Care
Zion United Church of Christ
Western Maryland Hospital Center
Community Education @ Washington County Hospital
American Pain Foundation
Chaplain Association of Tri-state Area
Washington County CARES Coalition

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Washington County CARES

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Priority Issues

The main concern of this committee has been identified and related to the current operations of our health care delivery system in terms of caring for those with chronic diseases, newly diagnosed end-stage diseases, and life-limiting illnesses. Based upon the experience of professionals within our community and as discovered with colleagues across the nation, we, as a society, do not have a comprehensive care management system designed to provide compassionate and quality care to this segment of the population and their care families. The rationale behind an improved system that gives optimal care for those living with chronic diseases, newly diagnosed end-stage diseases, and life-limiting illnesses and support for their families is that in models, such as hospice care, the gold standard for end-life care, the proven results show greater satisfaction in the care received and a physically and emotionally supported family as they provide care to their loved one.

If we are to approach the topic of improving end of life care, with the understanding of changing a cultural mind-set on death and dying in America, we must address the following issues that currently and over the next 10 years will prohibit us from being successful in supporting some of those at their most dignified time-end of life.

1. End of life care needs to be addressed at the point of diagnosis, where Advance Directives are discussed between the physician, patient, and family so that when acute episodes occur, physicians don't disregard the patient's Advance Directive at the urging of the family to "do something". Additionally, improved access to hospice care needs to be given (not just during the final days and weeks as is often experienced and patients must agree to "give up" treatments, such as palliative chemotherapy in order to receive hospice care).
2. Families are often required without the knowledge or skills necessary to coordinate and provide care for their loved one.
3. Patients are sent to specialists and there is not communication and coordination of the care for the patient. Many times services and medications are wasted or duplicated due to a lack of managed care. Conflicting information is given to the patient and family members, sometimes unintentionally or by specialists vs. PCP.
4. Many people are in denial and they are given false hope by the health care providers. A clear definition of what is a "terminal condition" is often misunderstood in the medical community; therefore, realistic hope instead of false hope is rarely given.
5. Non-English speaking patients and their cultures are unknown to the English speaking and traditional American health care providers.

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Barriers

Many barriers presented in communities today are not unique, but rather a reflection of our “American” culture at keeping death and dying at bay. As we discussed the situations faced daily by patients and health care professionals alike the following barriers were identified.

1. **Ineffective Communication**-Health care providers do not communicate with patients and families in the realm of long-term implications of their disease process and treatment. Patients and families are given little information and therefore are not able to adequately make “informed” decisions. Often patients endure long treatment regimens that will not cure them and had they been given the full perspective of their disease and the potential outcome of the treatment options, many would not give consent.
2. **Lack of Reimbursement**-Physicians are not reimbursed for having patient/family consultations on important issues related to care. Advance Directives are under utilized, sometimes as the result of the physician “knows best” simply because the time was not invested into ascertaining good dialogue with the patient and family. Many times physicians intimidate patients/families into decisions that they would otherwise not have made.
3. **Team Approach is Overlooked**-Only those patients that are enrolled in a hospice program receive the benefit of having a “team” focused approach to their care. We do not have this specialized format for patients newly diagnosed with a life-threatening illness or the support system for the family/primary care provider. Families are not seen as part of the “care team” and many times their input is overlooked or not sought. HIPPA regulations, while improving restrictions to patient information have made communication more difficult. Families lack education that the hospital is not the place to die.
4. **Spiritual Component is Too Late**-The differences between emotional and spiritual issues are many times unidentified. Spiritual care providers, such as clergy and chaplains many times are “after thoughts” and are not brought onto the team initially. Chaplains are not valued as part of the care team and are underpaid for their education and expertise. Lay clergy are often not equipped with the education that chaplains are to address issues related to complex situations surrounding end of life care.

5. Not a Place-Neither the hospital or the community has a facility, such as hospice house or special unit with directed end of life care. A lack of reimbursement for instances when nursing home beds and assisted living beds that are empty and could be utilized as palliative care beds and respite beds for patients/families. Expert staffing needed to handle the specialized care at end of life is minimal due to lack of education in the medical and nursing programs.

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Proposed Solution(s)

If we have any intentions on providing adequate health care for our aging population, there must be immediate consideration and administration of developing an Elder Care Management Model for End of Life Care. The development of the Elder Care Management Model could provide our aging population with appropriate and compassionate health care that would encompass not just the last 6 months of life, but rather it would be initiated at the beginning of the last phase of life to ensure that each individual's care would coincide with the goals set forth by that person and the health care providers involved with the designee's care. The End of Life committee, composed of professionals working in the field of health care, those of faith, and community clearly summarized that a plausible solution would need to encompass the professional and non-professional populations at large.

Professional Considerations

1. Restructure Medicare payment and reimbursement to physicians for EOL care for consultations with patients and families. Reimbursement structure would include a clause of accountability. Include into the Medicare Benefits a hospice type of program for patients living with chronic illnesses.
2. Medical and nursing schools should be mandated to teach EOL care that includes the physical and psychological aspects, spiritual, and family communication into their programs and not merely offer it as an elective.
3. Incentives for professionals to attend EOL continuing education programs. Physicians must receive continuing education on EOL as part of their license renewal.
4. Decrease the malpractice insurance.
5. Develop a nationwide database that contains Advance Directive wishes of individuals & a standard for updating, such as during a driving license renewal.

Non Professional Considerations

1. Develop and execute an awareness campaign for the general public on the importance of completing an Advance Directive.
2. Patients receive education from their care providers on the importance of the patient/family's role in the planning of their care. Most do not realize they are a valuable part of the team and need direction and education on their role(s).